

## Is there a cure?

Currently there is no cure for AKU, although painkillers and joint replacement surgery can relieve the symptoms.

There is a potential new medication called nitisinone which we are studying in an international clinical trial. Nitisinone reduces homogentisic acid (HGA), which causes the damage in AKU. For more information, please see the DevelopAKUre leaflet, available from the AKU Society ([www.akusociety.org](http://www.akusociety.org))

## How can I help?

We are always looking for people to volunteer – you could help with fundraising, managing our online communities, contacting AKU patients or even campaigning. If you are interested please contact us at [info@akusociety.org](mailto:info@akusociety.org)

To donate, please visit our fundraising page at [www.justgiving.com/alkaptonuria](http://www.justgiving.com/alkaptonuria). You can also donate by sending a cheque to our office address.

### AKU Society

66 Devonshire Road  
Cambridge  
CB1 2BL

Call us: 01223 322897

Contact us: [info@akusociety.org](mailto:info@akusociety.org)

Visit us: [www.akusociety.org](http://www.akusociety.org)

Please help us to cure AKU, a rare genetic disease, by donating online at: [www.justgiving.com/alkaptonuria](http://www.justgiving.com/alkaptonuria)

### Registered office:

The Alkaptonuria Society  
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Registered Charity in England and Wales: 1101052

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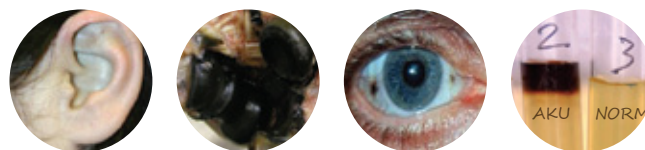
# What is Alkaptonuria?

AKU  
+ Alkaptonuria Society →

# What is Alkaptonuria

Alkaptonuria (AKU) is a rare genetic disease that causes bones to go black and brittle—hence why it's also called black bone disease.

AKU causes severe pain and disability as life progresses. It is inherited, meaning that it is passed on by both your parents. This makes it especially important for your brothers and sisters to check if they also have AKU.



## The Alkaptonuria Society

>  
Dr Nicolas Sireau  
Chairman  
Alkaptonuria Society



The AKU Society is a patient group supporting patients with AKU. Please contact us if you have any concerns about your disease. If you have questions about lifestyle, coping with AKU or the financial or social impact of AKU, we can help. Our medical director, Prof Ranganath, can offer medical advice and help to answer your questions.

## Symptoms:

- Black urine
- Black and brittle cartilage, leading to osteoarthritis
- Hardening of blood vessels, leading to risk of heart disease
- Black spots in the eyes
- Darkening of the ears

## Possible impact:

- Severe back and joint pain
- Kidney and prostate stones
- Heart disease
- Inability to work
- Social isolation and depression